

Originalartikel

# Directing the senses in the contemporary orientations to cancer disease control

## *Debating symptom research*

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*This paper discusses ongoing changes in orientations to cancer disease control in the Global North, particularly health promoter attempts to identify the early cancerous body. The paper suggests that the emphasis on early diagnosis of cancer aligns ideas on a symptomatic management of the public with a process in which 'what counts as cancer symptoms' is steadily being subdivided, classified and expanded. This alignment, the paper suggests, is an example of how biomedicine potentially extends its boundaries into everyday forms of embodied, social life by changing the social and moral value placed on bodily sensations. Also, the paper echoes ongoing conversations in medical anthropology on symptom experiences; suggesting that symptom experiences may be a suitable analytic axiom for exploring the relationship between biomedical knowledge production and embodied experience. It is suggested that an anthropology of sensations is a useful analytical framework for such explorations.*

## Introduction

The past decades' alleged 'war(s) on cancer' – reflected in massive financial flows, biotechnological innovations and changes in the organization of interventions and practices – have proven still more efficient leaving in its wake increasing cancer survival rates and the potential spread of 'survivor narratives' in Denmark as well as in other parts of the Global North (Rubin et al., 2015). In many ways, these changes may encourage us to think that we are entering a new social and cultural history of cancer that will eventually challenge notions of cancer as a signifier of death and degeneration, so poignantly discussed by Sontag (Sontag, 1983(1978)), as well as cancer's impact on individual and social lives. Concerted efforts to increase survival rates does, however, not only manifest in a multiplicity of meanings and associations attached to experiencing or dying from cancer. Rephrasing Paul Stoller, this paper suggests that ongoing changes in orientations to cancer disease control equally extend into 'the village of the healthy' as into 'the village of the sick' (2005).

Changes in the social and cultural history of cancer in Denmark and the Global North are characterized by changes in the orientation toward cancer disease control, where a focus on early diagnosis has been added to an already firmly established prevention discourse, or what Tørring (2014) has referred to as a reconceptualization of cancer as an acute disease<sup>1</sup>. During the past decade Denmark has witnessed an unprecedented transformation in the rationales underpinning cancer diagnostics (cf. Vedsted & Olesen, 2015). According to Tørring (2014) these shifts arose not only due to the interests of health promoters but were also made possible as a result of the intricate relationship that exists between collective cancer imaginaries, fears and available resources. Tørring (2014:15) suggests, for example, that the booming economy of the early twenty-first century, as well as a general politics of fear, made the introduction of early cancer diagnosis possible as it required a radical change in resource distribution. This paper expands on Tørring's cultural analysis of contemporary orientations toward cancer disease control; not by reflecting on its preconditions, but more on how biomedical knowledge production potentially extends its boundaries into everyday social life. Overall, the paper suggests that the emphasis on early diagnosis of cancer aligns ideas on a symptomatic management of the public with a process in which 'what counts as cancer symptoms' is steadily being subdivided, classified and expanded. The paper suggests that inquiries into the production of symptom categories may provide potential insights into the intricate relations between biomedical knowledge

production and embodied experience, and in particular how biomedicine adds to the building of what Kleinman and Fitz-Henry (2009) have tentatively referred to as the building of contemporary forms of disease sensitization - here defined as a form of embodied subjectivity (Whyte, 2005) characterized by the potential or the ever-present 'what if' brought on by our human desire to alleviate or prevent suffering disease.

The first part of the paper illustrates how a symptom management of the public has gained a powerful presence in contemporary orientations to cancer disease control. A presence which adds to a medical semiotics (Good, 1994) that directs awareness to the tangible, perceptible body and its cancer potentials; Is this tiredness a sign of disease? What should I think about my weight loss? It is suggested that a technologisation of biomedical practice such as exemplified by orientations to cancer diagnostics is increasingly tied up to sensorial experience. This leads to the second part of the paper, which contributes to an emergent critical literature on symptom experiences (cf. Hay, 2008; Risør, 2011, Hinton & Hinton, 2002). Anthropologists have for long been interested in the ways individuals ascribe meaning to symptom experiences, but only recently have this interest translated into more theoretical clarifications on how symptom experiences evolve in cycles of experience and articulation encompassing both individual and shared sensory categories. With few exceptions (cf. Lock, 1993; Hinton and Hinton, 2002; Kirmayer, 1992), anthropological research on symptom experiences have been occupied with their place in the narrative construction of illness experiences (cf. Garro, 1998) or their moral value and relation to bodily management or decision-making (cf. Hunt, 1998). Less focus has been directed to questions such as; How are bodily sensations experienced and articulated in the first place, and how or when they are directed towards the realm of illness?

Foucaultian inspired scholarship has done pioneering work on the reciprocal flow between power relations and 'the social domain' illustrating the productive forces of biopower in shaping the micro-politics of bodily management and perception (cf. Lock, 1993; Rose, 2007). It is thus well established that the body is both a biological phenomenon as well as a cultural product, and that discourse is 'part and parcel of processes of embodiment and sense-making' (Porcello et al., 2010:61). As noted by several scholars, it is the tracing out of the complex relations between these domains – or the tracing out of how biopower(s) become productive in the configuring of embodied experience – that is the remaining, ongoing project (Whyte, 2009; Porcello et al., 2010). Following the work of Hinton (2002, 2008) and Geurts (2002) along with others (e.g. Nichter, 2008; Hay, 2008) this paper

suggest that integrating research on sensorial experience with critical writings on discourse and biopower is one way to more fully articulate relations between biomedical knowledge and bodily experience; thus allowing us to 'do this tracking'. Following the proposition presented that our sensorium, defined as the bases of our perception and the seat of embodied sensation, is historically and socially constituted (Geurts, 2002), the paper thus echoes ongoing calls to explore symptom experiences as cultural configurations of sensation experience. Following Cameron Hay (2008) this may be epitomized as:

*A sensation is embodied; it is felt experience. By contrast, a symptom is a constructed and socially informed cognitive interpretation that indexes but is not itself an embodied sensation (Ibid.: 221).*

The argument presented is thus somewhat similar to critical approaches to the study of diagnostic categories as deep-seated, cultural assumptions about what it means to know the body, which sociologists and anthropologists have explored for the past decades (cf. Lock, 1993; Young, 1995). The production of diagnostic categories – it is well established – opens up new spaces for the production and articulation of different forms of distress and also shapes embodied experience. In the same way, approaching the production of symptom categories and exploring the connections between biomedical knowledge production and everyday embodied experience may lead to an understanding of the social and moral values placed on embodied sensations that 'shape that nascent zone, where sensation becomes conscious experience and undergoes a transformation to symptom' (Hinton and Hinton, 2002: 157).

## Methods

I have been affiliated with the Research Centre for Cancer Diagnosis in Primary Care at Aarhus University since its establishment by Danish epidemiologist Peter Vedsted in 2010. The commitment to the reflections brought forward in the paper is the result of yearlong research efforts exploring why and when people seek medical assistance (cf. Andersen, et al., 2010) as well as the centre's collective endeavours to critically study public health-related subjects such as delay in diagnosis and awareness (cf. Merrild, et al., 2016; Offersen, et al. 2017; Andersen & Risør, 2014). The analysis presented is the result of ongoing fieldwork I conducted

on Danish general practice as part of a cancer research environment as well as my access to epidemiological research environments; talks and discussions on clinical practice with colleagues working as doctors or in public health. Fieldwork has been reported elsewhere (cf. Andersen, Tørring, & Vedsted, 2014).

## Directing sensations in contemporary medicine

For the past decade Rose (2007), among others, has argued that we live in an age where biomedicine is redirecting the attention of our corporal existence to its diminutive parts, to the molecular level of existence, encouraging us to engage with, experience and imagine our bodies in particular ways. Contemporary biomedical truth games, Rose states,

*work at a molecular level, the level of neurons, receptor sites, neuron-transmitters, and the precise sequences of base pairs at particular locations in what we now think of as the human genome (Ibid.:26).*

In accordance with this line of thought Howes and Classen (2014) describe how the introduction of biotechnology has reduced the medical and clinical reality to that which meets the eye, suggesting that ‘the recording and communication of patient sensations’ (Ibid.:48) has become of still less importance to the everyday practice of medicine.

The corporeal re-direction or attention to the molecular level is also reflected in the search for the early cancerous body. In Denmark, pre-symptomatic cancer prevention practices, such as genetic counselling, is available for selected risk groups, defined by objectified knowledge on cancer heredity (e.g. BRCA-1 gene and risk of breast cancer) (cf. Svendsen, 2005). Moreover, during the past decade we have witnessed the introduction of a wide range of biomarkers (e.g. prostate-specific antigen) into clinical use. When I argue for a re-direction to the tactile body to sensations and their potential transformation into symptom experiences, it may thus appear as an appeal to engage with a topic from the past and of which techno-medicine, to stay with the terminology of Rose (2007:11), has lost interest. I will argue, however, that restraining ourselves to explore how biomedicine narrates disease at the molecular level is too narrow to achieve an understanding of the potential social implications of cancer disease control.

Despite its biotechnological alignments, cancer diagnostics is infinitely symptom based, which means that healthcare trajectories and the organisation of clinical practices depends on the categorisation and interpretation of the perceptible, tangible body and the translation (or redirection) of embodied sensations into potential symptoms of disease. Approximately 90% of all cancers diagnosed in Denmark begin with an individual's response to an embodied sensation and a decision to seek medical assistance, having to answer questions such as: Where does it hurt? What are your symptoms? As will be developed on in the below, an emphasis on symptom experiences as a way to manage cancer disease control forces an alignment with the senses, as it changes the social and moral values placed on bodily sensations such as tiredness, pains, a bloated stomach or those vague and intermittent, difficult-to-verbalise kinds of sensorial experiences that may be part of our everyday embodied ways of being-in-the world.

## Identifying the cancerous body

The reconceptualisation of cancer as an acute disease is a telling example of complex intertwining in action and can be viewed as a configuration of *biological*, *sociological* and *epidemiological* styles of thought (Hacking, 1990). Its reconceptualisation ties, for example, thoughts concerning exponential tumour growth and a moving towards death, with sociological ideas that affect the conduct of individuals and organisations, both bridged by epidemiological efforts to delineate with ever more accuracy 'the early symptoms' of cancer. In Denmark, this configuration is visible in the implementation of biotechnological innovations and increasing access to MR and CT scanners, which permit early detection of tumours and socio-politically enforced changes in the organisation of healthcare delivery. Since 2007 the Danish healthcare system has witnessed the implementation of more than 30 standardised cancer pathways, and Danish hospitals have invested a vast amount of resources to eliminate waiting times and to improve the organisation of diagnostic investigations (Probst, Hussain & Andersen, 2012). In the process of managing the public and implementing and administering the organisation of diagnostic practices, cancer symptoms have gained a powerful symbolic presence. The clinical guidelines on cancer pathways list, together with other forms of objectified clinical knowledge, such as age and smoking status, various symptoms which are used to sort patients when they access the healthcare system. The cancer pathway for ovarian cancer, for example, states that bodily sensations such as abdominal

bloating, nausea, lack of appetite, frequent urination, obstipation and tiredness should raise the suspicion of ovarian cancer and warrant a referral to a diagnostic fast-track pathway (Danish Health Authority, 2012).

Moreover, the Danish health authorities, as well as major patient organisations (e.g. The Danish Cancer Society) have launched national campaigns aimed at raising people's awareness of cancer symptoms and advocate seeking healthcare early. In the Danish Cancer Society's most recent national campaign, *'Know the seven signs'*, the public is encouraged to seek medical advice if experiencing prolonged coughing, unexplained weight loss, unexplained bleeding, changes in birthmarks, lumps, difficulties swallowing and changes in bowel movements (Danish Cancer Society 2015). In the material each symptom is described in detail, followed by visual images of ticking clocks and doctors announcing the importance of not delaying to take action. In a TV campaign the powerful and disastrous relation between the acuteness of cancer, lack of awareness and time-passing-by is portrayed in a sequence, where a man silently rests in a chair in front of his TV while not noticing that his house is catching fire. The overall message of the images and statements thus emphasise the dangers associated with failure to respond to (as well as recognise) embodied sensations as potential signs of a malignant disease.

Reference to symptom categories has thus gained a powerful symbolic presence in managing and reorganising cancer disease control in Denmark; objectified as abstract-able forms of body-knowledge that may propel people – the potential patients as well as health professionals – to consider whether a serious disease might be lurking in the(ir) body. Equally interesting is the fact that the presentation of cancer symptoms in public health rhetoric and clinical guidelines appears to build on a presumed capacity of epidemiological knowledge to form a new 'know how' that will ensure early diagnosis of cancer. In further underlining the importance of attending to symptoms I will go on to discuss what constitutes this 'know how'. In particular, I argue that cancer symptom categories can be understood as what Lock and Nguyen (2010:18) call techno-phenomena, in the sense that they are unstable, objectified forms of knowledge that configure in the interface 'between available technologies, clinical practices and preconditioned ways of seeing and understanding' (Ibid.). This is not to dispute that cancer or tumour growth is a biological phenomenon. Bodies harbour tumours that grow in size and produce altered physiological states that will at some point produce, for example aches and pains, bleeding or lumps that require attention, and tumours can cause death and suffering. But the question is how aches and pains end up being articulated as symptoms of cancer.



## *The search for early symptoms*

As Aronowits (2007) notes in his exploration of the social history of breast cancer, there was a remarkable stability throughout the twentieth century in what was considered the core list of cancer danger signs. For centuries the public was taught to respond to lumps or blood and to what was considered vaguer signs, for instance, 'a sore that does not heal, blood in stool or chronic indigestion' (Ibid.:145-146). Clinical or scientific reference to the alarming symptoms of cancer is thus not of recent origin, but systematic epidemiological interest in identifying early cancer symptoms began just a decade ago. The most influential, widespread studies are based on epidemiological research and are applied in clinical, general practice medicine (Hamilton, 2009; Jones, et al., 2007)<sup>2</sup>. In this literature alarm symptoms are defined as 'symptoms that are associated with a subsequently greatly elevated risk of serious disease being identified' (Ibid.:1). There is no consensus in clinical and epidemiological research, however, on the definition of 'a greatly elevated risk'. Moreover, the composition of contemporary categories of alarm symptoms does not transcend time and space. On the contrary, following Lock's (1993: xviii) reasoning on the factuality of menopause, we may see that it is a category 'with boundaries and meanings that shift depending upon the viewpoint and interests of speaker and listener'.

Contemporary scientific language on the classification of alarm symptoms of cancer is based on probability theory and developed to provide quantified probabilities on the risk of having a particular cancer disease when experiencing a specific bodily sensation. Apart from lumps, the majority of bodily sensations referred to as alarming in contemporary guidelines or campaigns (such as abdominal pain, changes in dietary habits, haemoptysis, cough and rectal bleeding) have estimated predictive values of approximately 0.4-5.0% among individuals who have sought medical advice. While risks estimates increase with age and with the presence of more symptoms, overall, the risk values presented in the epidemiological literature are quite low (Hamilton, 2009). From a semiotic perspective, this may prove troublesome as it makes distinguishing between normal and pathological signs difficult, that is 'symptoms' are iconic and can be interpreted widely (cf. Good, 1994; Hinton & Hinton, 2002). Among clinicians and in clinically oriented research this has spurred debate and concern on how to identify the potentially cancerous body from the non-sick bodies. From an epidemiological research perspective, low risk estimates, however fed into more reckonable discussions on *what* should be considered alarming: When a person present with



symptoms indicating a two percent risk? Or a five percent risk? Initially, leading epidemiologists suggested pursuing a five percent risk strategy (Jones et al., 2007); meaning that people presenting in general practice clinics with symptoms indicating a five percent risk of cancer should undergo diagnostic investigations. In the past five or six years, however, and as the reconceptualisation of cancer as an acute disease has gained political and public momentum, a more ideological position centring on the logic of urgency is taken, suggesting that the lower the threshold, the greater the probability of not overseeing a cancer diagnosis. Various examples of this exist in the UK and Denmark, which play a leading role in re-orienting cancer disease control in the Global North.

In the UK, two-week-wait national guidelines were implemented as early as the beginning of this century. Driven by attempts to further improve cancer prognosis horizons, and thus combat evidence showing that the UK lingers behind in international cancer survival comparisons, the National Health Services recently initiated a large national make-over of cancer diagnostic guidelines. Overall, and dominated by the logic of urgency, this make-over resulted in a lowering of risk thresholds. Leading epidemiologists in the field just published a report comprising lists of hundreds of cancer symptoms, specifying the symptoms or symptom groups warranting urgent intervention in detail (Nice Guideline, 2015). Moreover, electronic risk tools implemented in general practice medical records are being piloted to prompt general practitioners to consider a referral for further diagnostic investigations if people presenting in the clinic have an estimated 2% risk of having cancer, and national public awareness campaigns hearten people not to hesitate to see their doctor if they have even the vaguest signs of cancer. At the 8th Annual Meeting of the Cancer and Primary Care Research International Network held in 2015 at Aarhus University<sup>3</sup>, general practitioner and a leading UK stakeholder, Greg Rubin raised the issue that if a paradigmatic shift in cancer diagnostics is indeed underway then propensity screening is in effect becoming a fact as lowering risk thresholds opens the floodgates to the cancer diagnostic process. And I might add; the shift also means a change in the semiotics of medicine, implying that many more bodily sensations are translated into a potential cancer symptom.

While the socio-political framing of clinical guidelines in Denmark is somewhat different than in the UK<sup>4</sup>, Denmark is witnessing a similar process emphasising the importance of identifying the early symptoms. This process is in part driven by the implementation of the national cancer pathways in 2007-2009 but also enhanced by ongoing initiatives. Similar to the UK the success of ongoing changes in the healthcare system, and in particular the implementation of cancer diagno-

stic pathways, is systematically monitored by various actors: the Danish Regions, individual research teams and the Danish Cancer Society. Recently various publications concluded that the introduction of cancer pathways and the focus on increasing cancer awareness have had an impact on waiting times, but they also identified a new challenge: Only half of all cancer patients are diagnosed through cancer pathways, which means they most likely present with symptoms not described in the guidelines and thus do not warrant further diagnostic investigation (cf. Jensen et al., 2015). Leading Danish health promoters and early diagnosis advocates, such as the former head of the Danish Cancer Society, Frede Olsen, consequently argue for the implementation of more highly differentiated diagnostic pathways and the introduction of urgent referrals for people who present with what has been referred to as unspecific or low-risk, but not no-risk, symptoms (Vedsted & Olesen, 2015). Citing the highly influential UK-based epidemiologist Willie Hamilton, Vedsted and Olesen (2015:66) state in a recently published article in the high-impact journal *British Journal of Cancer*: 'A system that focusses on cancer diagnosis based on alarm symptoms alone might also be a healthcare system that favours the "sick-quick" and lets down the majority with vague symptoms'. Hamilton and his research group introduced the idea of low-risk-but-not-no-risk symptoms in 2009 as part of a process of changing diagnostic pathways in the UK. Using constipation as an example of a low-risk-but-not-no-risk symptom, they argued that:

*NICE guidance explicitly states that constipation does not qualify for urgent referral, despite this symptom having a risk of an underlying colorectal cancer of just under 1% in the over-40s once it has been reported to primary care. Patients with a low-risk symptom are not rare: less than half of colorectal cancer patients have a symptom qualifying for urgent referral (Hamilton, 2009:441).*

In Denmark diagnostic pathway subdivisions are not fully implemented, but research projects identifying the unspecific and low-risk-but-not-no-risk symptoms of diverse cancers have been initiated and early diagnosis advocates believe their implementation is will soon be underway. Importantly, ongoing debates about cancer diagnostics and low-risk-but-not-no-risk symptoms illustrate how identified flaws in cancer disease control are often met with further subdivisions and, of greater importance, how epidemiological fervour for classification results in a process where still more bodily sensations are transformed into potential symptoms of cancer. Hamilton et al. (2009) refer to a number of bodily changes such as constipation, tiredness or diarrhoea as low-risk-but-not-no-risk symptoms that

should warrant investigation. Changes which, as also stated 'when presented in general practices have 1% risk of having a cancer, but in a population who has not sought care is much, much lower' (Hamilton, 2009: x)<sup>5</sup>. Hamilton estimates, for example, that rectal bleeding has a predictive value of 0.1% in an epidemiological population that has not sought medical advice. Vague, which was what Vedsted and Olesen used, is thus a precise denominator for those kinds of symptom categories, reflecting the high level of statistical uncertainty involved in distinguishing the kinds of bodily sensations that constitute a need for diagnostic intervention. In accordance with Douglas (2001:147), we may say that the search for cancer symptoms reflects a scientific approach to the body that offers an extremely partial picture, 'pushing to the extremes the forensic aspects of certainty, and trying to extend the certainty-seeking practices of science'. In a search for certainty in terms of being certain to identify the early cancerous body, and in a search to identify the early cancer symptoms enabling the identification of the cancerous body, the epidemiologically-driven introduction of low-risk-but-not-no-risk symptoms is a process where what counts as cancer symptoms is steadily being subdivided, classified and, not least, expanded.

### *Technology and treatment imaginaries*

In her exploration of cancer narratives in the oncology ward, Delvecchio-Good (2001) argues that the presence of increasingly complex and innovative forms of biotechnology spark hope and treatment imaginaries that manifest in certain affective and economic flows, together establishing what she calls a biotechnical embrace, and which she sees manifest in the ways patients and oncologists narrate cancer disease trajectories in the US healthcare system. Increasing access to complex forms of biotechnology also plays a vital part in reorganising cancer disease control in the Danish setting. In this section, and in order to initiate reflections on cancer and disease sensitisation, I explore how the joining of the logic of urgency and increasing access to biotechnology 'sparks hope and treatment imaginaries' (Ibid.:397), but also adds a particular dimension of uncertainty to the classification and subdivision of symptom categories described above.

The introduction of magnetic resonance imaging (MRI) scanners in 1984 was an obvious influence preconditioning early diagnosis initiatives in Denmark. Since then, numerous other high-tech diagnostic tools have been introduced, allowing for still more detailed, easy access to bodily introspection. Computerised tomography (CT) scanners and access to digital imaging technologies have, for

example, altered diagnostic potential for lung cancers in Denmark (Guldbrandt et al., 2015), and the introduction of capsule endoscopy is expected to lead to earlier diagnosis of cancers in the bowel and throat. Biotechnologies naturally add corporeal and visual dimensions to cancer diagnostics but, as suggested above, they also call for an alignment with the senses. In the Danish context this has gradually altered definitions of what is considered pathological, resulting in the establishment of new sup-groups of people at risk<sup>6</sup> and, as illustrated in the above, stimulated by the predominant logic of urgency, it has prompted epidemiological goals to identify with still more accuracy the early cancer symptoms that match early pathological manifestations that are technologically visualised. Lung cancer diagnostics is a useful way to illustrate this circularity.

Lung cancer is deadly, with only a small minority (approx. 10%) of sufferers surviving beyond five years. According to a recent Danish study, this is partly because lung cancer patients are diagnosed at late, progressive disease stages (Guldbrandt et al., 2015). Vocal advocates of early diagnosis believe that organisational changes, easy access to diagnostic technologies and increased symptom awareness could change prognostic horizons for people with lung cancer. In Denmark this belief is reflected in organisational changes and easier access to diagnostic technology. It has also spurred clinical and epidemiological debates on how to identify the early symptoms of lung cancers as 'traditional' symptom categories, such as haemoptysis and severe dyspnoea, only tend to be present when the disease has progressed extensively and do not present in all patients. In order to identify early-stage lung cancer, vaguer symptoms such as cough, shortness of breath and tiredness are now increasingly considered symptoms of lung cancer (cf. Hamilton, 2012). A public debate between the Danish Cancer Society and a prominent TV doctor, Peter Qvortrup Geisling, highlights the dynamics of the logics and dilemmas this discussion contains.

As part of its 2014 'Know the seven signs' campaign, the Danish Cancer Society stated on its website that 400 people with lung cancer would have lived longer if they had sought healthcare when experiencing the early symptoms of cancer, leading to earlier diagnosis, which is naturally a seductive promise. The media generally does not question Danish Cancer Society campaigns and political activities, but Geisling publicly voiced reservations about the veracity of this statement. In a nationally broadcast radio interview with the Danish Cancer Society's director of research, he questioned whether people suffering from early-stage lung cancer actually experience clear and detectable symptoms. Geisling's main argument was that these people often cough because they smoke and the cance-

rous body does not necessarily appear any different than 'their normal body'. The research director's response was that some people have detectible symptoms and that improved strategies for identifying and communicating those symptoms, in addition to urging people to respond to them, would save lives: 'The point is not that people should be able to say that they have lung cancer. The point is that they should identify or detect changes in their bodies and seek medical advice on those changes' (P1, 21 January 2015).

Changes in cancer disease control are naturally driven by a multitude of actors and logics, and the Danish (and UK) cancer debate is much more multi-vocal than presented here. The above example, however, serves to illustrate how 'treatment imaginaries' (Good, 2001) that develop when reconceptualising cancer as an acute disease result in a drive to delineate the early symptoms of cancer that match the pathological discoveries made possible by technology. If stage two lung cancer is technologically-detectable, it initiates a process of identifying the cancer symptoms that match stage-two lung cancer. As touched upon previously, the example thus suggests that a technologisation of medical practices calls for an alignment with the world of the senses, as diagnostic practices involve an interpretation of the perceptible, tangible body and thus engage with the liminal border between sensation experience and symptom by encouraging reflections such as: might this tiredness be a symptom? Or 'why is my stomach bloated'?

### *Symptoms as cultural configurations*

In the final part of the paper I will briefly illustrate ways in which a medical anthropology of the senses can contribute to the study of symptom experiences and provide insights into the relations between biomedical knowledge production and embodied experience (cf. Andersen, Risør & Nichter, 2017). This section should merely be read a proposition for future research, not as a fully developed analysis of the social implications of contemporary orientations to cancer diagnostics such as explicated in the above.

In a special issue of *Transcultural Psychiatry* Hinton and Kirmayer (Hinton et al., 2008) together with Nichter (2008) and others (Hay, 2008) embarked on presenting an agenda to explore the relevance of the senses to medical anthropology. This agenda was inspired by cultural phenomenology (cf. Cordas, 1993) and what has been referred to as 'the sensorial turn' in the humanities (Howes and Classen, 2014), and primarily driven by an investigation and definition of what are bodily sensations. Sensations – as stated with Hay (2008) in the introduction – refers to

an embodied experience or a variety of somatic forms of experiences raging from feelings of heat in the body to dizziness, pains or palpitations (Hinton & Good, 2009:57). Overall, these authors depart in the proposition that sensory experience and meaning is equally physiological and cultural. Sensations such as dizziness, fatigue, pains or itching develop in a complex relationship between our different sense-modalities<sup>7</sup> and culturally acquired ways of somatic attention (Csordas 1993) – or what Hinton and colleagues refer to as sensation schemas (Hinton et al., 2008:152). Of central importance to this approach is a critique of universalist notions on human perception and sense modalities as well as anthropology's detour to discourse (cf. Geurts, 2002:10-12; Porcello et al., 2010). Following Geurts, our sensorium (or sensory order) is 'a pattern of relative importance and differential elaboration of the various senses through which children learn to perceive and experience the world' (2002:5), and which is a fundamental domain for cultural production, expression and communication. In a society (or for certain groups or individuals), certain senses and sensations may be foregrounded, thereby becoming key components of moral and social systems. Guerts (2002), for example, illustrates how the sense of balance is invested with great cultural significance among the Anlo-Ewe of Ghana, why signs of loss of hearing which impairs balance is given much attention. Similarly, Nichter's work on Ayurvedic medicine illustrates how experience of sensation and meaning is produced in relation to humoral knowledge-systems, where the body is equally calibrated and experienced through regimens of diet (Nichter, 2008). In their studies on panic attack, Hinton and colleagues have turned more specifically to explore what they call 'ethnophysiology-guided somatization' (Hinton and Good, 2009:64). Overall they suggest that different social and cultural groups have different panic ontologies<sup>8</sup> as well as different 'local biologies' (cf. Lock, 1993) resulting in very different manifestations of panic attack. Any sensation, this literature suggest, is thus produced and articulated in a cultural process – or what Hinton et al calls 'complex loops' (2008: 147) between culturally meaningful modes of attention and articulation, local biology and embodied experience<sup>9</sup>.

The agenda (or one of the agendas) for a medical anthropology of sensations then becomes one of understanding bodily sensations as culturally embedded, and to explore their production, as well as their meaning-base, and ask how sensations become filtered through idioms of distress (Nichter, 2008) – or considered 'a symptom'. Let me develop on this by returning to the cancer case and a brief empirical case from a clinical encounter that I witnessed during fieldwork in general practice clinics.



*Marianne is 54 and her life in many ways resembles general ideas of what constitutes a 'typical' Danish middleclass-life. Together with her husband and two nearly grown-up children she resides in a 1970s brick-house in a suburban neighborhood in Jutland. She has been working as a nurse for more than 25 years, and her husband is a former director of the local public school. I initially met Marianne when she was visiting her local general practice clinic, and I was able to join her for a consultation with her doctor, discussing what she referred to as 'her non-substantiated cancer scare' [ubegrundede eller hysteriske kræft-frygt]. When I visit her in her home a few days after having met in the clinic, we sit down in her kitchen and she shares with me reflections on getting older, and the difficulties she experience in articulating illness worries and deciding when to present them to her doctor. "I know that I am probably too young to worry about catching anything serious. But still, people around me fall ill... and all of a sudden it is actually something we discuss when I meet with my friends. "How is your cholesterol", and so on....And one day one of my close friends told me that she had been undergoing investigations for an ovarian cancer! It is absolutely horrible. She is too young, I think... But luckily they caught it 'in time'. She will undergo surgery and her changes are good. But then I started to worry, and all of a sudden I thought that my 'lower parts' felt strange, heavy, bloated... You know, I felt a presence of something...I wondered if it were actually any different than before... And then I went to see Thomas (her doctor). Luckily it is probably nothing to worry about, as he said. Still, I can't help but wonder.... However, I have decided that if it does not go away within a few weeks I will see him again. This heaviness... is that normal? And how can he be so sure?*

While this brief excerpt on Marianne's encounter with her doctor, Thomas, does not allow us to reflect in detail on the social processes through which she came to experience her body as potentially hiding a cancer, it does, however, accentuate the relevance of turning to symptom experiences as cultural configurations of sensorial experience.

In the medical literature symptoms have traditionally been defined as patients' subjective illness worries or presentations. WONCA, the international organization for general practitioners (GPs) and family physicians, for example, presented in 1995 an international glossary for general practice where a symptom was defined as '...any expression of a disturbed function or structure of the body and mind by a patient. Cough, pain, and tiredness are symptoms' (Bentzen, 1995:133). Following this line of reflection, the reference to cancer by Marianne may be viewed as her subjective way of interpreting her symptoms; she experiences symptoms



and interprets them as potential signs of cancer. Taking a sensorial approach, we are, however, encouraged to ask, why or how she came to attend to her feeling heavy as 'a disturbed function', or how this 'disturbed function' was processed in the first place. In this sense Marianne's symptom experiences are not just expressions of *her* subjective concerns of a 'disturbed function', nor are they mere parts of an ongoing illness narrative through which she gives meaning to existing sufferings. Rather, we may hypothesize that Marianne's embodied experiences and her way of being attentive to her body and providing meaning to the 'heaviness in her lower parts' configures in the intersection between her everyday life-world; through engaging with friends and family and through her/their encounters with contemporary biomedical discourse on cancer disease control. In order to emphasize this point, let us briefly jump to another ethnographic location. As noted by Julie Livingston (2012) in her ethnographic work on cancer care in Botswana, the political and economic context of cancer provides a particular local scene for the performance and experience of cancer. In Botswana – her work reminds us – people do not worry about having an insidious cancer growing inside the confines of their bodies, such as Marianne does. In Botswana cancer 'is there' when tumors appear in the sensory company of pain and suffering, simply because cancer is performed without the remote structures of prevention or oncology. To quote Livingston,

*'cancers' visibility or invisibility in a given population is created through a dense network of knowledge accumulation and production, and this network is uneven or lacking in many parts of Africa (2012:33).*

As suggested here, contemporary changes in the social and cultural history of cancer in Denmark do in many ways resemble the opposite of Livingstone's Botswana. In Botswana, we may imagine how people are taught endurance or 'bodily ignorance'. While in Denmark the public is encouraged to be vigilant, aware and respond with urgency if they sense even the slightest change in their bodies, as this is the cocktail that may change (or revert) cancer prognostic horizons. But how may we understand such differences? Imagine Marianne in Botswana; would she simply have ignored the 'heaviness in her stomach'? Thinking that no doctor would be able to help her? Or would she not even have experienced it? That is, would 'the heaviness' not have stood out from the everyday passive endurance of embodied existence 'as something to pay attention to'? Or would it simply not have been there? We do not know. Taking the proposition by Hinton (2002, 2008),

Geurts (2002) and other sensorially oriented scholars seriously, we are, however, encouraged to reflect on the possibility of both. Contemporary orientations to cancer diagnostics provide a moral and interpretative ground for the way Marianne articulates her embodied experiences and it exemplifies more general trends in how biomedical knowledge systems become key in framing both the organization and articulation of sensorial experience.

The case of Marianne is not meant to suggest that there is a simple relation between the introduction of cancer diagnostic practices and the particular sensations expressed by Marianne. It is meant as an illustration of how a medical anthropology of sensations may provide us with insights into the complex relations between technology and sensing, suggesting that the sensorial is an interesting site for exploring how symptom experiences configure in the intersection between physiology and culture, and helping us to understand how or why particular readings of the body become foregrounded (cf. Guerts, 2002). Moreover, I believe it illustrates how an increasing access to biotechnology forms a broad alignment with the senses; not just emphasizing the importance of visual access to the corporal, such as suggested in the literature (cf. Howes & Classen, 2014). This leads me to a final consideration of what I hinted at as *contemporary forms of disease sensitisation* in the introduction of the paper.

### *Disease sensitisation*

According to Merriam-Webster's Dictionary, 'sensitisation' is 'the process of becoming highly sensitive to specific events or situations' and, more specifically in reference to medicine, it means being more sensitive towards 'a specific serum' (Merriam-Webster, 20 November, 2016). Disease sensitisation, I, however, suggest, may refer to an embodied form of being; a form of being where one is sensitive towards ideas, connotations or signs of disease. Conceptually, it goes beyond an ordinary understanding of awareness, which often refers to the more cognitive process of linking knowledge and experience (Good, 1994), and it also departs from ideas concerning pathologisation, which refers to feeling sick or diseased (Conrad, 2007:11-12). Rather, disease sensitisation, this paper suggests, refers to an embodied form of experience, reflecting on the 'what if', and where sensation meaning and experience is produced in a social context where disease prevention is invested with great cultural significance (cf. Offersen et al, 2016). There is thus an intriguing parallel to contemporary theorizing about the subjunctive mood, such as for example presented by Susan Whyte (2005:251). Subjunctivity,

according to Whyte, is that mood of a verb used to express supposition, desire, hypothesis and possibility rather than to state an actual fact. It is distinguished from indicative, imperative which is the voice of certainty. In Whyte's work on the Ngyole in Uganda the subjunctive mood is one of hope, doubt and potential, and is often expressed as the possibility that healing practices, such as a ritual, might alleviate suffering. She describes this as the practicing of healthcare in the subjunctive mood.

In this paper, disease sensitisation is not necessarily related to a particular kind of practice. Rather, I suggest it may be seen as a form of embodied subjunctivity, characterised by the potential, or the ever-present 'what if' brought on by our contemporary desire to alleviate or prevent suffering, such as exemplified in the above presented discussion on cancer disease control. As we learned through our brief encounter with Marianne, it was her socially required knowledge on cancer risks, her mutual hope of 'being early' and her fear of cancer that organized her bodily attention as well as gave meaning to her experiences. But it was not stable meaning, in the sense that there was just one reading of her 'feeling heavy'; it was an embodied form of subjunctivity organized and produced by the uncertain and cultural significance placed on contemporary diagnostic practices. Access to biotechnology and a resourceful socio-political setting keen on winning the war on cancer, thus aligns with the senses by changing the social and moral landscape in which sensations are produced and experienced.

Future, sensorially engaged research is suitable for studying such social change, and for asking how or why contemporary forms of disease sensitisation make more and more people adopt risk roles (Frumer, n.d.); explore social differences in how people negotiate access to care (Merrild et al., 2016) or narrate everyday forms of embodiment and reflect on 'am I fine or sick'? (Offersen et al., 2017; Hay, 2008). Moreover, future research will provide us with more insights into how the building of disease sensitisation will change or revert the prognostic horizons of some, lead others to over-diagnosis, or challenge the allocation of resources due to increasing pressure on the healthcare system.

## Conclusion

In this paper I have highlighted ongoing changes in orientations to cancer disease control, particularly health promoter attempts to identify the early cancer-

rous body in Denmark and the UK. The paper suggests that the emphasis on early diagnosis of cancer aligns ideas on a symptomatic management of the public with a process in which 'what counts as cancer symptoms' is steadily being subdivided, classified and expanded. This alignment, the paper suggests, is an example of how biomedicine potentially extends its boundaries into everyday forms of embodied, social life by changing the social and moral value placed on bodily sensations. Moreover, the paper echoes ongoing conversations in medical anthropology on symptom experiences; suggesting that symptom experiences may be a suitable analytic axiom for exploring the relationship between biomedical knowledge production and embodied experience. Exemplified by reference to cancer, the paper encourages explorations into the production of symptom categories, not merely, however, as discursive cultural categories providing meaning to embodied experiences, but as a cultural production that may feed into existing cultural order of sensations. Lastly, I outlined an anthropology of sensations as a framework for understanding symptoms as cultural configurations and briefly illustrated its utility for exploring more overall relations between biomedical knowledge production and everyday, embodied experience and the building of contemporary forms of disease sensitisation.

## Noter

<sup>1</sup> As also touched upon by Tørring (2014), *acute* in medical terms refers to disease states that typically have very quick onsets. The idea of aligning cancer diagnostics with ideas of 'acuteness' was launched by health promoters in Denmark around 2006 and 2007, and it was apparently considered a suitable strategy to eradicate the idea of cancer as a slow growing disease, making manifest the importance of *early* diagnosis as a means to change cancer diagnostic horizons.

<sup>2</sup> The systematic identification and classification of symptom categories also resembles the classificatory logics dominating contemporary forms of evidence-based medicine (EBM) and its emphasis on clinical guidelines. The timing of this increased focus on symptom management may also be a result of the wider introduction of EBM in general practice clinics in the Global North.

<sup>3</sup> This conference is also known as the CaPri-Meeting (Cancer in Primary Care) and it was established by key cancer health promoters in 2007.

<sup>4</sup> Danish general practice clinical guidelines are less rigid than similar guidelines in the UK, allowing Danish general practitioners a more flexible, interpretive role

than their UK counterparts. Moreover, the Danish guidelines do not operate with at 2% risk threshold.

<sup>5</sup> This relates to another aspect of the argument for seeing alarm symptoms as techno-phenomena which deserves a brief mention here. Categories of cancer symptoms are produced in case-control studies conducted on patient files in UK primary care clinics. The risk estimates produced are thus a reflection of a selected epidemiological population consisting of people who sought medical assistance. Moreover, what people experience and report about their bodies in a general practice clinic is not, in essence, the same kind of information that is transformed into patient journal data. Basically, this means that the empirical material used in the production of cancer symptom categories is dependent on categorisation practices at clinical level (i.e. what is noted in patient files) and healthcare-seeking practices (i.e. what people present to their doctors and who seeks medical advice). If public healthcare-seeking practices or clinical practices change, the epidemiological population change, resulting in changed estimated risk levels and hence, fundamentally, what are considered cancer symptoms.

<sup>6</sup> Recent changes in lung cancer diagnostics has, for example, resulted in an increase in an 'at risk group' of people with nodules in their lungs. A nodule is an elevated area of tissue that may – or may not – develop into a malignant form of lung cancer. This group of people (in Denmark currently accounting for approx. 20-25% of those given the option of a CT scan) is encouraged to do follow-up scans for up to two years after their initial diagnostic investigation (Guldbrandt et al., 2015).

<sup>7</sup> Conversations on human sense-modals date back to Aristotle and his presentation of the five-sense-modal. See Geurts (2002:5-7) for detailed discussions of this, and why the 'five-sense-model' should not be regarded a scientific or even relevant cultural model for our understanding of the senses.

<sup>8</sup> Hinton and Good exemplify this by reference to muscle soreness. Joint pain and muscle soreness among Americans may for example cause worry about having a chronic disease such as fibromyalgia, while muscle soreness among Khmer refugees may indicate blockage of vessels possible causing limb paralysis (2009:64-64).

<sup>9</sup> There is much more to be said on the different theoretical assumptions (and differences) in this literature. See e.g. Nichter (2008), Hinton & Hinton (2002), Hinton and Good (2009) et al for more detailed proposals of the conceptual constructs of relevance for a medical anthropology of sensations.

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